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## Status exploration and analysis of regional hospice and palliative care networks in Germany: A protocol for a mixed-methods study --Manuscript Draft--

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<b>Full Title:</b>	Status exploration and analysis of regional hospice and palliative care networks in Germany: A protocol for a mixed-methods study
<b>Short Title:</b>	Status exploration and analysis of regional hospice and palliative care networks in Germany
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<b>Keywords:</b>	Palliative Care, Healthcare network, Maturity Model,
<b>Abstract:</b>	<p>Background</p> <p>Multi-professional cooperation between healthcare providers is a key quality criterion of hospice and palliative care. While hospice and palliative care networks can support cooperation on a local level, opportunities for wider cooperation through the establishment and development of regional hospice and palliative care networks in Germany have not yet been explored systematically.</p> <p>Aims</p> <p>The HOPAN study aims at: (1) identifying regional hospice and palliative care networks in Germany, (2) analysing these networks using an adapted quality assessment tool, and (3) proposing setting-sensitive recommendations for network development and exploring the benefits of these recommendations.</p> <p>Methods</p> <p>HOPAN is a prospective, observational, mixed-methods study comprising three work packages (WPs). In WP1, the stock of regional hospice and palliative care networks in Germany will be identified via database, literature, and internet research. In WP2a, focus groups will be conducted to adapt an existing maturity model for healthcare networks to regional hospice and palliative care networks. In WP2b, a questionnaire will be sent to each identified regional hospice and palliative care network to gain insight into their structure and status of development. In WP2c, group discussions will be conducted to develop setting-sensitive recommendations for these networks. Finally, in WP3, these recommendations will be sent to all participating hospice and palliative care networks, and the benefits of the recommendations will be evaluated via a questionnaire.</p> <p>Discussion</p> <p>Empirically developed setting-sensitive recommendations should enable the systematic establishment and management of regional hospice and palliative care networks in Germany, considering the specific needs and potential of each network. The study findings are expected to improve the overall development of hospice and palliative care services.</p> <p>Trial registration</p> <p>The study was prospectively registered in the German Clinical Trials Register (Deutsches Register Klinischer Studien) (Registration N° DRKS00030629; date of registration: 02 November 2022). The study is searchable under the International Clinical Trials Registry Platform Search Portal of the World Health Organization, under the German Clinical Trials Register number.</p>

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The study was approved on 20 August 2022 by the Ethics Committee of Hannover Medical School (N° 10424\_BO\_S\_2022) and the appointed data protection officer of Hannover Medical School. Prior to administering the questionnaire, the researchers will provide eligible participants with detailed information about the study type, content, purpose, and duration.

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- Give the name of the institutional review board or ethics committee that approved the study
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1 **Title**

2 Status exploration and analysis of regional hospice and palliative care networks in Germany: A  
3 protocol for a mixed-methods study

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20 not involved in the study design, the preparation of this paper, or the decision to submit the paper  
21 for publication. The funding body will not be involved in the collection, analysis, or interpretation of  
22 the study data. The funding body has reviewed this study protocol.



23 **Competing interests**

24 The authors declare that they have no competing interests.

25 **Data availability**

26 Data sharing is not applicable to this article, as no datasets have yet been generated or analysed for  
27 the current study.

28

29

## Abstract

### 30 **Background**

31 Multi-professional cooperation between healthcare providers is a key quality criterion of hospice and  
32 palliative care. While hospice and palliative care networks can support cooperation on a local level,  
33 opportunities for wider cooperation through the establishment and development of regional hospice  
34 and palliative care networks in Germany have not yet been explored systematically.

### 35 **Aims**

36 The HOPAN study aims at: (1) identifying regional hospice and palliative care networks in Germany,  
37 (2) analysing these networks using an adapted quality assessment tool, and (3) proposing setting-  
38 sensitive recommendations for network development and exploring the benefits of these  
39 recommendations.

### 40 **Methods**

41 HOPAN is a prospective, observational, mixed-methods study comprising three work packages (WPs).  
42 In WP1, the stock of regional hospice and palliative care networks in Germany will be identified via  
43 database, literature, and internet research. In WP2a, focus groups will be conducted to adapt an  
44 existing maturity model for healthcare networks to regional hospice and palliative care networks. In  
45 WP2b, a questionnaire will be sent to each identified regional hospice and palliative care network to  
46 gain insight into their structure and status of development. In WP2c, group discussions will be  
47 conducted to develop setting-sensitive recommendations for these networks. Finally, in WP3, these  
48 recommendations will be sent to all participating hospice and palliative care networks, and the  
49 benefits of the recommendations will be evaluated via a questionnaire.

### 50 **Discussion**

51 Empirically developed setting-sensitive recommendations should enable the systematic  
52 establishment and management of regional hospice and palliative care networks in Germany,  
53 considering the specific needs and potential of each network. The study findings are expected to  
54 improve the overall development of hospice and palliative care services.

#### 55 **Trial registration**

56 The study was prospectively registered in the German Clinical Trials Register (Deutsches Register  
57 Klinischer Studien) (Registration N° DRKS00030629; date of registration: 02 November 2022). The  
58 study is searchable under the International Clinical Trials Registry Platform Search Portal of the World  
59 Health Organization, under the German Clinical Trials Register number.

#### 60 **Introduction**

61 Until recently, some federal states in Germany promoted hospice and palliative care networks on a  
62 voluntary basis; however, most networks were financed by the donations and fees of network  
63 members (3-7). To improve on this situation, in 2021, the German legislature passed a new law  
64 (Gesetz zur Weiterentwicklung der Gesundheitsversorgung/GVWG) providing for the promotion of  
65 regional hospice and palliative networks (1). The aim of this legislation is to improve multi-  
66 professional and cross-sectoral cooperation in hospice and palliative care at a regional level, via  
67 network coordinators, funded by statutory health insurance (8). Specifically, coordinators are tasked  
68 to: (a) support cooperation and coordination between network members, (b) support joint public  
69 relations, (c) initiate and organise further and advanced training programmes, (d) organise regular  
70 network meetings, and (e) cooperate with other regional counselling services (2).

71 A comprehensive overview of regional hospice and palliative care networks in Germany is lacking. To  
72 date, only two smaller surveys at the level of individual federal states have been conducted (5, 7).

73 One study published regional recommendations for the implementation and coordination of hospice  
74 and palliative care networks (9), showing that the investigated networks differed considerably

75 regarding their stages of development, organisational structures, fields of activity and working  
76 methods (6).

77 In hospice and palliative care, healthcare providers and volunteers must collaborate to improve the  
78 quality of life of patients and their families (10). Cooperation between providers in care networks  
79 enables a seamless interplay of all healthcare professionals and volunteers, thereby improving the  
80 continuity of patient care (11, 12).

81 On a regional level, collaboration between healthcare providers in hospice and palliative care seems  
82 to positively impact individual casework (13). According to the literature, regional networks may  
83 increase the number of personal meetings between healthcare providers and increase members'  
84 willingness to cooperate (14). Hence, regional networks may improve inter-professional  
85 communication among healthcare providers, evoke confidence in action, reduce stress among  
86 employees, ensure the early integration of psychosocial and spiritual support, and reduce the  
87 number of hospital admissions (15). They may also promote joint initiatives for the further  
88 development of local hospice and palliative care services and improve the organisation of patient-  
89 centred care (13, 14).

90 Until recently, the establishment and development of regional hospice and palliative care networks  
91 in Germany was largely unsystematic. These networks were not integrated into the German  
92 healthcare system and structural standards and quality indices for network collaboration and  
93 coordination were lacking.

## 94 **Materials and Methods**

### 95 **Study aim**

96 The project "HOPAN – Status exploration and analysis of regional hospice and palliative care  
97 networks using an adapted quality assessment tool" has the following three objectives:

98 (1) to identify regional hospice and palliative care networks in Germany,

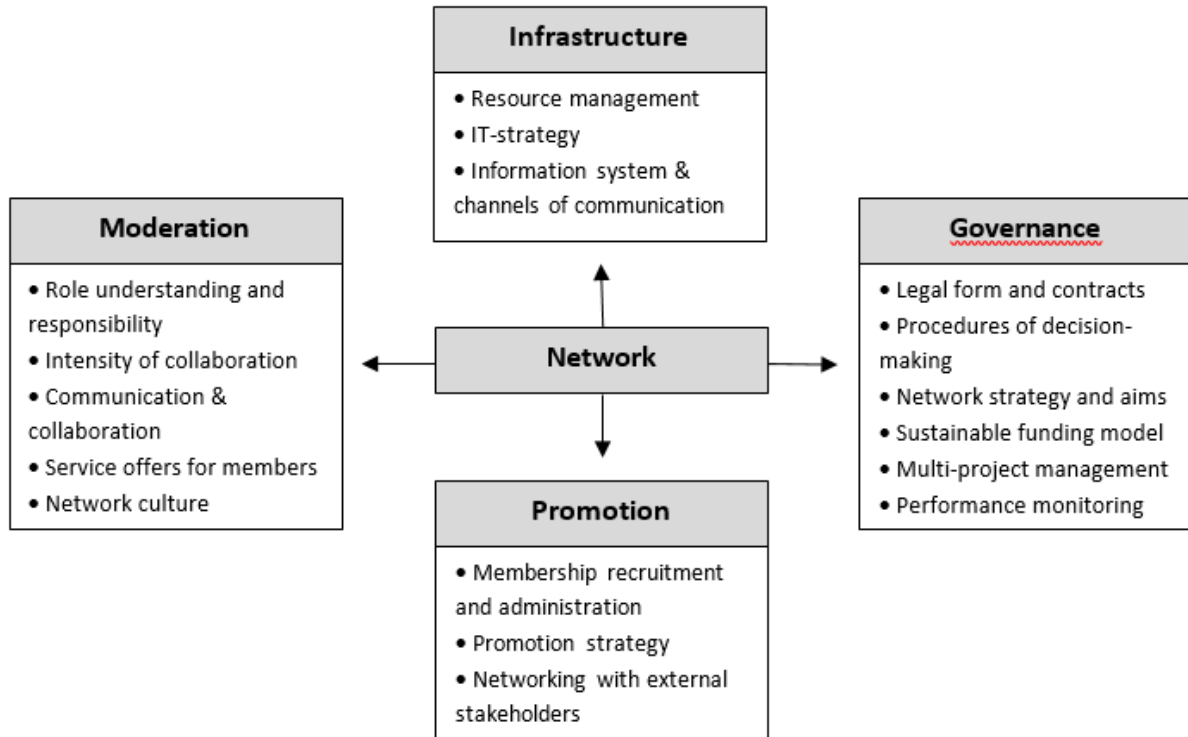
99 (2) to analyse these networks using an adapted quality assessment tool, and

100 (3) to propose setting-sensitive recommendations for further network development and to explore  
101 the benefits of these recommendations.

## 102 **Design**

103 HOPAN is a prospective, observational, mixed-methods study organised into three working packages  
104 (WPs). The study protocol adheres to STROBE guidelines (13). WP1 will involve the identification of  
105 regional hospice and palliative care networks in Germany via database, literature and internet  
106 research. The findings will provide an overview of the number and regional distribution of hospice  
107 and palliative networks in Germany.

108 In WP2a, an existing maturity model for healthcare networks, developed within the INDiGeR  
109 research project, will be adapted to accommodate the structures and contents of the identified  
110 regional hospice and palliative care networks (18). The INDiGeR research aimed at identifying the  
111 most relevant dimensions of successful network management and developing general  
112 recommendations for the implementation and improvement of healthcare and service networks. The  
113 project identified four key dimensions of network management: (a) infrastructure, (b) governance,  
114 (c) promotion, and (d) moderation (see Fig. 1).



115

116 *Figure 1: Key dimensions of network management from the INDiGeR project (18) (authors' own*  
 117 *translation into English)*

118 The maturity model focuses on the common provision of services from a single network perspective.

119 This methodological tool will be adapted for application to hospice and palliative networks.

120 In WP2a, a group of experts will be formed on the basis of the survey results (WP1) with the leaders

121 (e.g. coordinators, moderators) of hospice and palliative care networks in Germany and other

122 network experts. Expert group workshops will examine the extent to which the maturity model

123 should be supplemented and modified to accommodate hospice and palliative care networks, and

124 how the four relevant network dimensions (i.e. infrastructure, moderation, governance, promotion)

125 should be specified and operationalised. This specified and adapted maturity model will form the

126 basis for the model-based network analysis in WP2b.

127 In WP2b, the adopted maturity model for regional hospice and palliative care networks will be  
128 operationalised into questionnaire items. Subsequently, an online survey will be administered to all  
129 of the identified networks. The survey is expected to comprise three sections:

130 (a) A general section on the networks' basic and structural data (e.g. year of founding, number of  
131 partners, participating care actors, number of meetings per year).

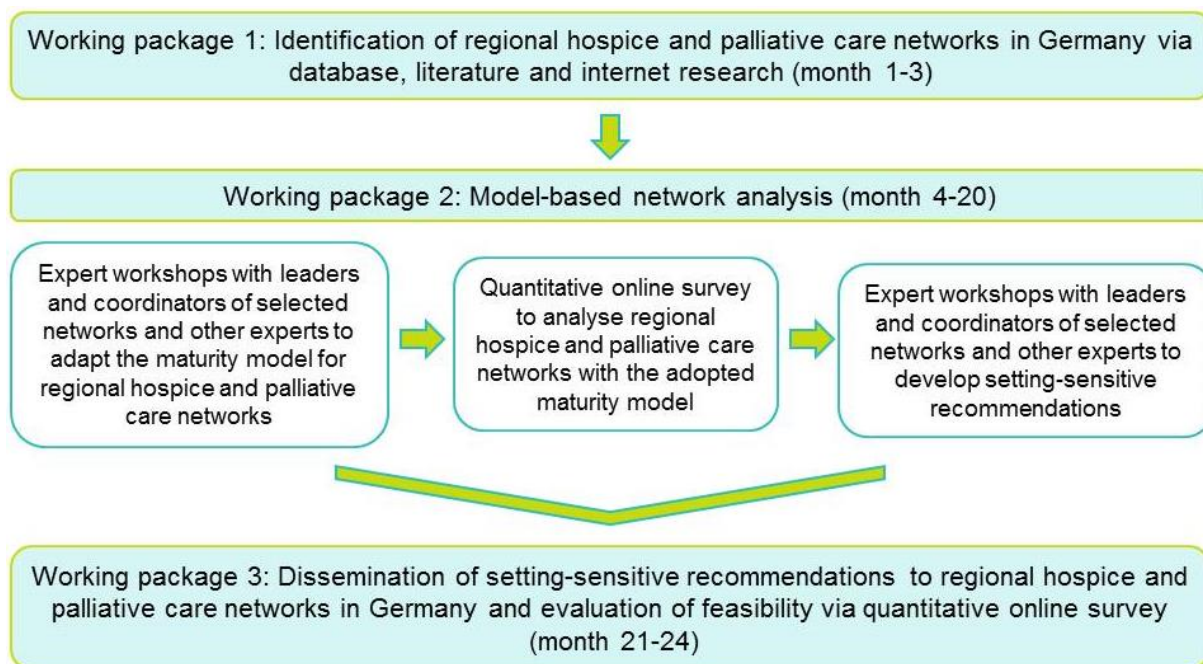
132 (b) A specific section on the model-based network evaluation, focussing on network dimensions and  
133 the degrees identified in WP2a (e.g. for network moderation: role understanding and responsibility,  
134 intensity of cooperation, communication, services offered to network members, network culture).  
135 Specific items will be associated with each sub-dimension, graded in four levels (e.g. initial,  
136 structured, established, optimised). Based on the results, a developmental status will be assigned to  
137 each dimension.

138 (c) A retrospective section on good practice and experiences of network development. Each  
139 dimension or sub-dimension will be specifically queried, to generate practical examples for the  
140 development of recommendations in WP2c.

141 In WP2c, four expert workshops with the abovementioned network leaders and coordinators ( $n=10$ )  
142 will be conducted to develop setting-sensitive recommendations for regional hospice and palliative  
143 care networks, on the basis of the results from WP2b.

144 In WP3, the recommendations arising out of WP2c will be disseminated to individual networks and  
145 usability will be evaluated. Each network surveyed in WP2b will receive setting-sensitive, individual  
146 recommendations, according to the network's maturity level. Additionally, each network will receive  
147 a link to a quantitative, standardised, online questionnaire to evaluate the utility of the  
148 recommendations. This questionnaire will be developed a priori by the research team and will  
149 contain questions on the usefulness of the recommendations in their respective dimensions, as well  
150 as the actual and planned implementation of the recommendations. The link to the online  
151 questionnaire will be sent to the networks using the survey software SoSciSurvey (SoSci Survey

152 GmbH, 2006–2022). The primary aim will be to explore the relevance and feasibility of the setting-  
153 sensitive recommendations. Finally, the maturity model and its level-specific recommendations will  
154 be adapted in accordance with the survey results and prepared for regional hospice and palliative  
155 care networks, so it can be used by: (a) further regional hospices and networks for the purpose of  
156 self-assessment and (b) health insurance providers for the purposes of quality assessment and  
157 reporting.



158

159 *Figure 2: HOPAN study design*

### 160 **Study population and data collection**

161 In WP1, all regional hospice and palliative care networks in Germany will be identified as completely  
162 as possible. The total stock of such networks in Germany is currently unknown. Hence, the size of this  
163 population can only be estimated. Based on the identified hospice and palliative care networks in  
164 Lower Saxony (19) and Bavaria (20), a total of 150 networks in Germany is estimated. Data will be  
165 collected via internet and literature research, supplemented by a search of national databases, such  
166 as the publicly accessible palliative care portal [12], the “Wegweiser Hospiz- und Palliativversorgung  
167 Deutschland” [37], and partly available lists of health ministries and state coordination offices [14].



168 Network names, contact details, regions, and other relevant and available information (e.g. year of  
169 founding, legal formation, sponsorship) will be recorded.

170 The group of experts, which will be set up in WP2a, will include leaders ( $n=10$ ; e.g. coordinators,  
171 moderators) of hospice and palliative care networks in Germany and other network experts from  
172 hospice and palliative care facilities in Germany. Participating network leaders ( $n=7-8$ ) will be  
173 selected from the group of networks identified in WP1. The selection will follow the maximum  
174 variation sampling strategy, based on criteria that have not yet been defined (e.g. size, duration of  
175 existence, degree of professionalisation). Moreover, a small number of experts ( $n=2-3$ ) will be  
176 recruited from the group of network members, based on the suggestions of cooperating German  
177 professional hospice and palliative care associations. If experts decline to participate in the study, the  
178 expert group will be supplemented on the basis of the same sampling criteria.

179 A total of  $n=5$  expert workshops are planned, each involving  $n=10$  of the abovementioned leaders  
180 and coordinators. Four of these meetings will be conducted as online video conferences. The first  
181 workshop will explore the extent to which the structure of the INDiGeR maturity model should be  
182 augmented and modified to accommodate hospice and palliative care networks. Members of the  
183 research team will send literature on the maturity model to participants prior to the workshop, and  
184 then present the model to participants at the workshop. The subsequent three workshops will aim at  
185 concretising and operationalising the assumed relevant network dimensions (i.e. infrastructure,  
186 moderation, governance, promotion) for regional hospice and palliative care networks. The  
187 documented results of the workshops will be compiled, reflected upon, discussed, and integrated by  
188 the research team and further developed into a maturity model for regional hospice and palliative  
189 care networks. The developed model will then be presented to the experts for their feedback in a  
190 further online workshop. In the expert workshops, established methods for moderating group  
191 discussions (e.g. card queries, World Cafe) will be used. Each workshop will be 3 hours in duration,  
192 and will be audio recorded and transcribed verbatim.

193 In WP2b, the respective leaders/coordinators of an estimated  $n=150$  hospice and palliative care  
194 networks will be sent an online survey. A response rate of 70% is expected, and thus  $n=105$  valid data  
195 sets to include in the analysis. Notwithstanding this calculated response rate, the aim will be to  
196 include as many as possible of the networks identified in WP1, in order to increase statistical power,  
197 especially for the more detailed network analysis.

198 In WP2c, expert workshops ( $n=4$ ) with the abovementioned network leaders/coordinators ( $n=10$ ) will  
199 be conducted to develop setting-sensitive recommendations for regional hospice and palliative care  
200 networks. For this purpose, the results of the network analysis for the individual dimensions of the  
201 maturity model (including the level-specific locations of the networks) will be presented as impulse  
202 speech. In group discussions, participants will develop specific recommendations for the further  
203 development of networks for each development level and sub-dimension. Each workshop will be 3  
204 hours in duration, and will be audio recorded and transcribed verbatim. An overlap of participants in  
205 WP2a and WP2c will promote participants' long-term commitment to and identification with the  
206 project.

207 In WP3, all networks that participated in WP2b will be administered a quantitative online survey. A  
208 total of  $n=105$  participating networks in WP2b and a response rate of 70% are assumed. Hence, 74  
209 valid data sets are expected for inclusion in the analysis. Respondents will indicate on a 4-point  
210 verbal rating scale the extent to which they deem the individual recommendations relevant and  
211 feasible for their own network. They will also be afforded the opportunity to make suggestions for  
212 improvement, via free text comments.

### 213 **Inclusion and exclusion criteria**

214 WP2a and WP2c will include leaders (e.g., coordinators, moderators) of hospice and palliative care  
215 networks in Germany and other network experts from the field of hospice and palliative care in  
216 Germany. All participants will be aged  $\geq 18$  years and have theoretical and/or practical knowledge  
217 and/or experience of hospice and palliative care networks in Germany.

218 After receiving detailed information about the type, content, and purpose of the study and their  
219 participation, experts will provide written informed consent to participate. Experts of all genders and  
220 ethnic backgrounds will be invited to participate.

221 Experts will be excluded from the study if they are insufficiently proficient in the German language to  
222 join group discussions and/or if they do not consent to participate.

### 223 **Ethical considerations**

224 The study was approved on 20 August 2022 by the Ethics Committee of Hannover Medical School (N°  
225 10424\_BO\_S\_2022) and the appointed data protection officer of Hannover Medical School. Prior to  
226 administering the questionnaire, the researchers will provide eligible participants with detailed  
227 information about the study type, content, purpose, and duration.

228 All study participants will be informed in detail, orally and in writing, about the project aims and  
229 expected outputs, before confirming their participation in the project. Participation will only be  
230 possible when the individual explicitly agrees to participate in the study and signs a written consent  
231 form. Each participant will have the right to refuse or discontinue participation at any time without  
232 providing any reasons for doing so.

233 The study results (e.g. transcripts) will be stored pseudonymously on the secure servers of the MHH,  
234 in order to ensure personal data protection and prevent the results from being linked to individual  
235 participants.

### 236 **Data analysis**

237 The data analysis will aim at describing the current stock of regional hospice and palliative care  
238 networks in Germany and determining setting-sensitive recommendations for the further  
239 development of these structures.

240 In WP1, data from the national database, internet, and literature searches will be transferred to a  
241 Microsoft Excel 2016 spreadsheet. Key characteristics of the identified institutions will be

242 documented in a template, according to availability (e.g. network name, district, federal state,  
243 contact person, contact address, legal formation, year of founding, region [urban/rural], and number  
244 of members). Additionally, quantitative data will be analysed descriptively using IBM SPSS Statistics  
245 27 (SPSS Inc., Chicago, IL, USA) for Windows. The survey will provide an overview of the number and  
246 regional distribution of hospice and palliative care networks in Germany.

247 In WP2a, the expert workshops ( $n=5$ ) with  $n=10$  participants (each) will be audio recorded and  
248 transcribed verbatim. Visual data, including the findings of card queries and World Cafes, will be  
249 photographed. Both oral and visual data will be analysed according to qualitative content analysis,  
250 using MAXQDA 2022 (VERBI Software Consult Sozialforschung GmbH, 1989–2022) (21).

251 In WP2b, the results of the online survey will be analysed descriptively and with frequency tables,  
252 using IBM SPSS Statistics 27. If possible, cluster analyses will be conducted to identify similar  
253 structures and different network types (e.g. “public/outward-oriented networks” vs.  
254 “member/inward-oriented networks”). Free text answers regarding network management will be  
255 inductively categorised, summarised, and evaluated using frequency counting.

256 In WP2c, the transcripts of the expert group discussions will be analysed according to qualitative  
257 content analysis, using MAXQDA 2022. A deductive coding procedure will be used, whereby the  
258 levels and sub-dimensions of the maturity model specified in WP2a will function as categories. The  
259 research team will review the recommendations in terms of coherence and adapt the wording as  
260 needed.

261 In WP3, quantitative data from the online survey will be analysed descriptively, using IBM SPSS  
262 Statistics 27. Free text comments will be analysed descriptively, in terms of content.

263 Figure 2 provides an overview of the mixed-methods study design across the three WPs. The figure  
264 illustrates the methods that will be used to develop setting-sensitive recommendations for regional  
265 hospice and palliative care networks in Germany.

266 **Expected results**

267 The main expected results are: (1) an overview of existing regional hospice and palliative care  
268 networks in Germany, (2) a maturity model for regional hospice and palliative care networks, (3) a  
269 model-based network analysis, and (4) setting-sensitive recommendations for the further  
270 development of each network. These findings will contribute to the further development of hospice  
271 and palliative care services in Germany, on a wider scale.

272 **Study risks**

273 Access to experts and leaders/coordinators of hospice and palliative care networks can be difficult,  
274 depending on their workloads and basic attitudes towards and experience with research projects.  
275 Hence, reaching the required number of participants may be a methodological challenge. However,  
276 achievement of the case numbers seems feasible, since the majority of the WPs involving  
277 leaders/coordinators are based on a qualitative research design, and the case numbers were  
278 calculated generously. Also, recruitment will be broad.

279 For the nationwide identification of regional hospice and palliative care networks, cooperative  
280 agreements will be made with all of the relevant associations, ensuring access to the relevant  
281 databases (“Wegweiser Hospiz- und Palliativversorgung” [37]) and network coordinators. In addition,  
282 the status analysis will be supplemented by an independent internet search for each federal state.  
283 This staggered procedure will ensure that networks are comprehensively identified and addressed.  
284 Furthermore, it is expected that the networks will have an intrinsic interest in participating in the  
285 project, in order to benefit from the specific recommendations for network development.

286 **Study status and timeline**

287 The HOPAN study is scheduled to start in January 2023, spanning 2 years.

288

## Discussion

### 289 **Limitations of the study design**

290 The HOPAN study will use a broad research strategy to identify regional hospice and palliative care  
291 networks in Germany. However, since new funding opportunities for hospice and palliative care  
292 networks were established in April 2022, it is expected that further networks will emerge during the  
293 course of the study. The research team will ask all partners to inform them of all emerging networks,  
294 in order for these networks to be invited to participate in the study. Nonetheless, a complete survey  
295 of all existing networks cannot be guaranteed.

296 The network analysis will be based on qualitative and quantitative data collected from network  
297 coordinators and leaders. Thus, the HOPAN study will specifically reflect the perspectives of these  
298 network coordinators and leaders, while omitting the perspectives of other network members, as  
299 well as patients and family caregivers. Hence, the study will not be able to evaluate the impact of  
300 hospice and palliative care networks on the quality of patient care.

### 301 **Dissemination and implementation**

302 To promote the accessibility and longevity of the research data and results, the research team will  
303 report the study findings in a comprehensive and transparent manner. Regardless of the findings, the  
304 research team will produce national and international congress presentations and peer-reviewed  
305 publications (published as open access, where possible). Data files with no personal identifying  
306 information will be kept after the study completion. In accordance with the American Psychological  
307 Association Code of Ethics, Sec. 8.14, "Sharing Research Data for Verification" [38], the study leader  
308 will not withhold any unidentifiable data from other researchers who wish to verify the conclusions  
309 of the author(s). Researchers who wish to use HOPAN study data to answer new research questions  
310 must obtain prior permission from the research group and author(s).

311

312 The results may be used directly by eligible networks in Germany (of which there are approximately  
313 400) to improve their network structure and work. Based on the level-specific recommendations,

314 each network will receive suggestions for further development and optimisation, tailored to the  
315 individual network status, thus enabling a process-oriented network development geared towards  
316 regional structures. The specified maturity model will ensure that all relevant network dimensions  
317 are considered. The recommendations are expected to support network coordinators' efforts to  
318 specify their field of activity, and to be used for training and the further education of network leaders  
319 and coordinators in hospice and palliative care. The project results may also be used for quality  
320 assessment and quality management in regional hospice and palliative care networks.

### 321 **Conclusion**

322 The present study protocol explains the purpose, significance, and scope of the mixed-methods study  
323 HOPAN, as well as its study design. The recommendations developed in this study are expected to  
324 optimise the establishment and development of regional hospice and palliative care networks in  
325 Germany, by ensuring better network coordination and promoting the development of regional  
326 hospice and palliative care structures. This improved networking is likely to have a positive effect on  
327 the quality of care in hospice and palliative care. The adapted maturity model will be initially  
328 published in digital form. If necessary, the model will be further developed in a follow-up project into  
329 a digital self-assessment tool for networks, which will automatically show level-specific  
330 recommendations relevant to the self-location. In addition, the status analysis and maturity model  
331 may be used in the longer term as evaluation tools (e.g. by health insurance providers to fulfil their  
332 reporting obligations to the Federal Ministry of Health).

333 The aim of publishing the present study protocol is to promote transparency by facilitating open  
334 access to comprehensive study details that extend beyond the summary publicised in the German  
335 Clinical Trials Register. Moreover, the study protocol may serve as a point of reference to the  
336 scientific community and other parties interested in the scientific and ethical aspects of the study,  
337 and prevent unnecessary duplication.

338

339 **Author contributions**

340 SvS, CB, FAH, TS, SSt, and NSch developed the original study plan, wrote the grant application, and  
341 obtained funding. SvS developed the manuscript on the basis of the original German grant  
342 application. CB, FAH, TS, SSt, and NSch enhanced the quality of the draft manuscript by revising it  
343 critically. All authors read and approved the final manuscript.

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347 **Supporting information**

348 STROBE-Checklist



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